Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence

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Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence

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ABSTRACT

Objective Improving dementia care is a policy priority nationally and internationally; there is a "diagnosis gap" with less than half of cases of dementia ever diagnosed. In English Health Department's Quality and Outcomes Framework (QOF) encourages primary care recognition and recording of dementia. The codes for dementia are complex with the possibility of under-identification through miscoding. We developed guidance on coding of dementia; we report the impact of applying this to 'clean up' dementia coding and records at a practice level.

Design The guidance had 5 elements: (i) identify Read codes for dementia; (ii) access QOF dementia register; (iii) generate lists of patients who may have dementia; (iv) compare search with QOF data; (v) review cases. In each practice one GP conducted the exercise. The numbers on dementia QOF registers before and after the exercise were recorded with the hours taken to complete the exercise.

Setting London primary care

Participants 23 (85%) of 27 practices participated, covering 79,312 (19,562 over 65s).

Outcomes Numbers on dementia QOF registers; time taken.

Results The numbers on dementia QOF registers increased from 1,007 to 1,139 (χ^2 8.17, p=0.004), raising identification rates by 8.8%. It took 4.7 hours per practice on average.

Conclusions These data demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the dementia identification rate. An improvement of 8.8% between 2011 and 2012 is equivalent to that on the fourth most improved PCT in the UK. In absolute terms, if this effect were mirrored across UK primary care, the number of cases with dementia identified would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46% to 54.8%. Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care.

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ARTICLE SUMMARY

Article focus

- Closing the “diagnosis gap” in dementia is a clinical and policy priority
- The primary care codes used for dementia in the UK are complex with the possibility of under-identification through miscoding.
- We developed guidance on coding of dementia and tested its impact on dementia coding and records at a practice level.

Key messages

- Applying the guidance resulted in a statistically significant increase in the numbers on dementia QOF registers, raising identification rates by 8.8%
- These data demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the dementia identification rate.
- If this effect were mirrored across UK primary care, the number of cases with dementia identified would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46.0% to 54.8%.

Strengths and limitations of this study

- The GPs who took part in this exercise were highly motivated and had been selected to participate in the NHS London dementia fellowship programme
- Generalisability may be limited from these London practices to those in the rest of the UK
- However, the coding systems used and GP information systems vary little so the demonstration that this exercise worked in practices across London may point its being applicable across the UK.
- We achieved a high participation rate and the practices covered a large population (179,312) over a wide and socio-demographically varied set of areas spread across 19 boroughs.
- The protocol generated was simple and required no training

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BACKGROUND

Dementia is one of the most common and serious disorders in later life with a prevalence of 5% and an incidence of 2% per year in the over 65s.[1, 2] In the UK estimates suggest there are 800,000 people with dementia currently.[3] It causes irreversible decline in global intellectual, social and physical functioning. Abnormalities in behaviour, insight and judgement are part of the disorder, as are neuropsychiatric symptoms such as psychosis, anxiety and depression. The economic cost of caring for people with dementia is immense. In the UK the costs of dementia are around £17 billion per year;[3] with some suggesting this is more than stroke, heart disease and cancer.[4] More importantly, the negative impacts of dementia on those with the disorder, in terms of deteriorating function, and on carers[5, 6] are profound. Worldwide there are 35 million people with dementia and this costs $600 billion per year, with these numbers set to double and the costs to at least triple in the next 20 years.[7,8]

The need to improve care for people with dementia is a policy priority nationally and internationally.[9-12] One common finding in analyses of health systems with respect to dementia is that there is a “diagnosis gap” in dementia with less than a half of those with dementia ever attracting a diagnosis of dementia. Also, such diagnosis and contact often occurs late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed. A common element of health strategies to improve the quality of care of people with dementia is the injunction that diagnosis rates should be increased and that diagnosis should be “early” or “timely”.

Part of the Department for Heath for England’s response to this has been to encourage primary care recognition and recording of dementia through its Quality and Outcomes Framework (QOF).[13] This is designed to incentivise, via payment, primary care services to improve the quality of care by standardising improvements in the delivery of primary medical services. The relevant indicators for 2013/2014 include:

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DEM001 The contractor establishes and maintains a register of patients diagnosed with dementia.

The numbers of people with dementia identified on these registers compared with projected numbers from the local age and gender structure has been used as a marker of progress against the goals of the National Dementia Strategy using a commissioned dementia prevalence calculator.[14] Using this methodology, figures from the Alzheimer's Society suggest that diagnosis rates in Britain range from 32% in the East Riding of Yorkshire to 76% in Belfast.[15]

These dementia registers rely on how dementia is coded in primary care record systems. This is generally via Read Codes which are a coded thesaurus of clinical terms that has been used within primary care in the NHS since 1985. The codes available for dementia are complex with the possibility of under-identification through miscoding. NHS London's therefore developed guidance on the coding of dementia (Web Appendix 1). In this paper we report the impact of applying this guidance in a sample of GP practices across London to investigate whether it is possible to raise diagnosis rates through undertaking an exercise to 'clean up' dementia coding and records at a practice level.

METHOD

A coding exercise protocol was developed to enable GPs to conduct a review of practice records and to recode cases where needed. This was developed by PR and SB iteratively with key stakeholders, facilitated by NHS London co-ordinated by JW. The protocol is presented in full in Table 1. This consisted of a simple 5 point process:

Step 1 – Identify commonly used Read codes for dementia/memory concerns

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Step 2 – Obtain practice's QOF dementia register

Step 3 – Run searches to generate lists of patients who may have dementia

Step 4 – Compare search results with QOF dementia register

Step 5 – Discuss patients for further review

Participating practices were drawn from boroughs across London who had a GP on the 2012/13 NHS London GP Dementia Fellowship Programme. The exercise was completed by the GP on the programme in each practice as set out in the Table 1. The numbers identified with dementia on the practice QOF registers before and after the exercise were recorded as were the hours taken to complete the exercise.

RESULTS

Sample

Twenty three (85%) out of the 27 practices available participated. These came from 19 boroughs across London. The participating practices had a practice population of 179,312 with 19,562 (10.9%) over the age of 65. The mean practice size was 8,296 (range 2,543 to 16,700). In terms of representativeness of the sample this proportion over 65 years old was similar to the overall percentage for London (11.2%); the London rate is lower than that for the UK as a whole (16.9%).

Impact of the intervention

The number of people on the practices' dementia QOF registers before the intervention was 1,007; after there were 1,139 cases on the registers. This was a statistically significant increase (χ^2 8.17, p=0.004). The mean number of people on the practices' dementia QOF registers before the intervention was 44 (range 0 to 232, standard deviation (sd) 49). After there was an average of 50 cases on the registers (range 0 to 248, sd 54). Taking the

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numbers aged 65+ in each practice as the denominator, this represents an identified prevalence of 5.1% before the intervention and 5.8% after. Using the most recent DH estimates,[14] the expected number of people with dementia in London is 69,849 which equates to a prevalence of 8.11% of those aged 65+. We used this to calculate the identification rate before and after the intervention. After the intervention 71.8% of cases of dementia were identified compared with 63.0% before. The effect of the intervention was therefore to increase the rate of identification of dementia in this sample by 8.8%.

Cost of the intervention

The only cost of the intervention was the person time spent on the exercise which took an average of 4.7 hours per practice.

DISCUSSION

The data presented here demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the rate of identification of cases of dementia. In this sample of GP practices in London, an 8.8% improvement was achieved at a cost of an average 4.7 hours of GP time.

Size of effect

We need to consider the meaning of the 8.8% increase observed. In their recent analysis of identification rates from QOF registers across the UK, [15] the Alzheimer's Society calculated for each Primary Care Trust (PCT) area (the forerunners to current Clinical Commissioning Groups (CCGs)) identification rates in the same way that we have here. They did this for 2011 and 2012 and calculated changes in numbers and rank between 2012 and 2011. In rank terms, for a PCT an improvement of 8.8% between 2011 and 2012 would have resulted in that PCT being the fourth most improved PCT in the UK (displacing Torbay who achieved an 8.2% improvement). In terms of ranking, an improvement of 8.8% would

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have moved a PCT up an indicative 68 places (out of 178). In absolute terms, if this were implemented across UK primary care with the same aggregate effect the number of cases with dementia identified on QOF registers would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46.0% to 54.8%.

Reasons for coding error

Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care. Completing the exercise also sheds some light on the reasons for the current coding errors. Part of this may be a wish to avoid labelling patients as having dementia on the QOF register unless there is a high level of certainty as to the diagnosis. This is an understandable and reasonable concern, as there is stigma associated with the diagnosis, and professional attitudes to and confidence in the management of dementia may play a role in perceived under-recognition. However, all the cases re-assigned in this exercise were those with an established dementia. The issues seemed more a function of computer and coding systems. This points to the potential value of exercises such as this. 98% of London practices use EMIS or Vision systems; these require coding by V2-5byte Read codes. In this system there are a large number of potential dementia-related Read codes that might be used and these are not presented in a way that is user friendly (Web Appendix 1). In this exercise we sought to address this by operationalising how these codes should be used. Equally the letters received by GPs from secondary care services where diagnoses may have been made were often not clear in terms of diagnosis and diagnostic category. Letters from psychiatric services were often long with the diagnosis often hidden in the text. We also found cases where the first assessment letter referred to “probable dementia” but where the definitive diagnosis in a letter 3-6 months later had not led to the coding being brought up to date. The use of multiple systems and unfamiliar terminologies by secondary care leads to confusion and lack of clarity in coding within primary care. The simple expedient of all secondary care clearly stating the ICD 10 codes or the most appropriate Read code to use would address this coding problem.

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Limitations

This is a simple pragmatic study and the limitations of this exercise and the data presented here need to be considered. This was not a random sample of practices or of GPs. The GPs who took part in this exercise were highly motivated and had been selected to participate in the NHS London dementia fellowship programme. They were therefore interested in dementia and also built skills during the programme within which the exercise was completed. The main likely impact of this may have been to enable them to complete the exercise more quickly than the average GP. However, even if the exercise took twice the time, this would mean that it could be achieved in a single day. The generalisability of the practices within which the exercise was completed also needs to be considered. All were group practices and they were similar to the rest of London in terms of age structure, however the practices studied had a higher than average recognition rate before the exercise (63.0%) compared with the UK as a whole (46.0%). This may reflect the interests of the participating GPs and their effect on coding in those practices. This is of interest because this suggests that we were intervening in practice systems that may have been more optimised than others might be. It is quite possible that in less optimised systems there might be greater levels of coding error and so an even greater effect might be achieved. As an estimate of effect our results might therefore be considered conservative. There will be differences between London practices and those in the rest of the UK as evidenced by the difference in age structure in London compared with the UK as a whole. However, the coding systems used and GP information systems vary less, and so the demonstration that this exercise worked in practices across London may point its being applicable across the UK. Different countries have different systems and it is likely that the detail of the approach here will only apply to the UK, however the general issue of clarity in coding is likely to be of importance internationally. There are strengths in the approach used. We achieved a high participation rate and the practices covered a large population (179,312) over a wide and socio-demographically varied set of areas spread across 19

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boroughs. Also, the protocol generated was simple and required no training. The data here represent a test of the feasibility of conducting the exercise and of the content of the protocol.

Conclusions

It is important to be clear that this coding exercise would form only a part of comprehensive whole system effort to improve dementia care and to lift diagnosis rates through initiatives such as: education and training, memory service commissioning, and service improvement. But, the results presented here suggest that completing this exercise could provide a simple, cheap and useful first step to improve accuracy of records. More accurate information can help improve the management of patients and also help to close the diagnosis gap.[11, 16] In terms of next steps, evaluations of its effect in a more representative sample of practices nationwide would be of use. But equally, given its simplicity and low cost, it may be that practices and CCGs would wish to implement this without needing further evaluation other than auditing local effects. In this paper we provide all the materials needed to carry out the exercise.

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WEB APPENDIX 1 – LONDON DEMENTIA CODING GUIDANCE

Guidance on Dementia Coding

NHS London

What is the big issue for London GPs in coding dementia?

There is a dementia diagnosis gap of 52% in London, which means that only 48% of those who we would expect to have dementia, based on population prevalence rates, are recorded on GP practice dementia registers[1]. We believe one of the reasons behind this apparently low diagnosis rate is a lack of accurate coding due to there being confusion with the available codes. This note for GPs contains guidance to help with this.

Why is it so important diagnose and accurately code dementia?

1. It means the patient's care can be planned, managed and monitored, so that they can be signposted to supportive services and prescribed appropriate medication.
2. Diagnosis gives power to the patient and their families, as it brings clarity in terms of what is happening to them, and provides them with the ability to make choices themselves (National Dementia Strategy, 2009).
3. The coding of dementia and putting the patient on the dementia register means we can develop an accurate picture of London dementia rates to inform commissioning of high quality, cost effective services in response.
4. It means that GPs can see their own practice performance rise, and give patients confidence as they can see the identification rates on www.myhealthlondon.nhs.uk

Making dementia coding simple

The coding of dementia can be less than straightforward, so a team of GPs working to improve dementia care in London, with support from specialist experts, has put together this GP dementia coding guideline.

Guideline

1. We propose the use of four codes in primary care, which are listed below.
2. If the specific type of dementia is unknown, for whatever reason, please use the code Eu02z "Unspecified dementia". This can always be changed later when more information is available. Please do not use 1461.00 "h/o dementia", 28E..00 "cognitive decline" or similar codes for this purpose – these do not allow aggregation.
3. Where some diagnostic data are available the codes Eu00. can be used for Alzheimer's disease, Eu002 for mixed dementia, and Eu01. for vascular dementia. All others can be given Eu02z.
4. A full list dementia codes can be found below. This matches ICD10 codes to recognised general practice dementia READ codes. Where detailed information on subtype of dementia is available, then these can be used.

The main codes which General Practitioners should use to code for dementia in primary care are:

ICD		Read
F00	Dementia in Alzheimer's disease	Eu00.
F00.2	Dementia in Alzheimer's disease, atypical or mixed type ("Mixed Dementia")	Eu002
F01	Vascular dementia	Eu01.
F03	Unspecified dementia	Eu02z

[1] QOF data, 2010/11

Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia Feb, 2012

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ICD10		READ
F00	Dementia in Alzheimer's disease	Eu00.
F00.0	Dementia in Alzheimer's disease with early onset	Eu000
F00.1	Dementia in Alzheimer's disease with late onset	Eu001
F00.2	Dementia in Alzheimer's disease, atypical or mixed type	Eu002
F00.9	Dementia in Alzheimer's disease, unspecified	Eu00z
F01	Vascular dementia Arteriosceloritic dementia	Eu01. E004
F01.1	Multi-infarct dementia	Eu011
F01.2	Subcortical vascular dementia	Eu012
F01.3	Mixed cortical and subcortical vascular dementia	Eu013
F01.8	Other vascular dementia	Eu01y
F01.9	Vascular dementia, unspecified Uncomplicated arteriosclerotic dementia Arteriosclerotic dementia with delirium Arteriosclerotic dementia with paranoia Arteriosclerotic dementia with depression Arteriosclerotic dementia NOS	Eu01z E0040 E0041 E0042 E0043 E004z
F02	Dementia in other diseases classified elsewhere	Eu02.
F02.0	Dementia in Pick's disease	Eu020
F02.1	Dementia in Creutzfeldt-Jakob disease	Eu021
F02.2	Dementia in Huntingdon's disease	Eu022
F02.3	Dementia in Parkinson's disease	Eu023
F02.4	Dementia in HIV disease	Eu024
F02.8	Dementia in other disease classified elsewhere Dementia in conditions	Eu02y E041
F03	Unspecified dementia Presenile dementia Uncomplicated presenile dementia Presenile dementia with delirium Presenile dementia with paranoia Presenile dementia with depression Presenile dementia NOS Uncomplicated senile dementia Senile dementia with depressive or paranoid features Senile dementia with paranoia Senile dementia with depression Senile dementia with depressive or paranoid features NOS	Eu02z E001. E0010 E0011 E0012 E0013 E001z E000 E002. E0020 E0021 E002z

ICD10		READ
F05.1	Delirium superimposed on dementia Senile dementia with delirium	Eu041 E003
F05.9	Delirium, unspecified	Eu04z
F06.0	Organic hallucinosis Other senile and presenile organic psychoses Senile or presenile psychoses	Eu050 E00y E00z
F06.7	Mild cognitive disorder	Eu057
F10.7	Residual and late onset psychotic disorder due to alcohol. Including; - Alcoholic dementia - Other alcoholic dementia - Chronic alcoholic brain syndrome	Eu107 Eu10711 E012 E0120
G30 G30.8 G30.9	Alzheimer's disease Other Alzheimer's disease Alzheimer's disease, unspecified	F110.
G30.0	Alzheimer's disease with early onset	F1100
G30.1	Alzheimer's disease with late onset	F1101
G31.0	Circumscribed brain atrophy Including; - Fronto-temporal dementia - Pick's disease - Progressive isolated aphasia	 No Code F111.
G31.1	Senile degeneration of the brain, not elsewhere classified	F112.
G31.8	Other specified degenerative disease of the nervous system Including - Grey matter degeneration - Lewy body disease - Lewy body dementia - Subacute necrotizing encephalopathy	 F116 Eu025

"Knowledge is power with respect to diagnosis, giving those affected and their families an understanding of what is happening and the ability to make choices themselves"

National Dementia Strategy, 2009

For a copy of the London Dementia Needs Assessment or any queries about dementia diagnosis and care, please get in touch with Jen.Watt@london.nhs.uk ; 020 7932 2646

Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia Feb, 2012

Table 1: Dementia coding exercise protocol

Dementia "Coding Clean-up" Exercise:
Improving records of dementia diagnosis in your practice by more accurate coding

Introduction - why is this important? Achieving early diagnosis of dementia is a major national priority, identified in the National Dementia Strategy and championed by the Government. Only 46% of those who we would expect to have dementia in London, based on population prevalence rates, are recorded on GP practice dementia registers[1]. We believe one of the reasons behind this low diagnosis rate is problems in coding. We have previously developed guidance for GPs to support them to code dementia diagnoses accurately (see Appendix 4).

Aims The following exercise has been primarily designed to support GPs to identify problems in coding, which are contributing to low rates of dementia diagnosis on practice registers. It also provides a framework for GPs, to consider other patients who may have dementia, but are not yet diagnosed. It may also identify patients who have been lost to follow-up, which GPs can then address following local pathways.

Method

Step 1 – Identify commonly used Read codes for dementia/memory concerns At a practice meeting, discuss what codes GPs in your practice use when adding dementia or worries about memory to a patient's problem list. Make a note of codes commonly used by your colleagues. Add any codes commonly used that are not already included on the list[2] in step 3 below.

Step 2 – Obtain Practice's QOF dementia register Find the QOF dementia register for your practice[3]. Write the number of patients currently on the register, on the form in Appendix 3.

Step 3 – Run searches to generate lists of patients who may have dementia[4] Run the following searches:

1. All those prescribed anti-dementia medication (See Appendix 2)
2. "h/o dementia" Read code 1461.00
3. "Dementia monitoring" Read code 66h..00
4. "Dementia annual review" Read code 6AB..00
5. "Cognitive decline" Read code 28E..00

[1] Dementia Prevalence Calculator, 2013
[2] These are the Read codes that were identified by the London pilot as being most commonly used. There is, however, variation from practice to practice, so it is important to have the discussion with colleagues, to identify codes your practice commonly uses. For example, other codes used in some practices in the pilot were: "Forgetful", "Organic memory impairment", "Short Term Memory Loss"
[3] For EMIS and Vision, the codes that place patients on the QOF dementia register can be found in Appendix 1

[4] It is possible that this part of the exercise can be done by your practice manager/ administrator

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6. "Confusion" Read code R009.00
7. "Memory loss Symptom" Read code 1B1A.
8. "Memory Impairment" Read code Z7CEH
9. "Short Term Memory Problems" Read code Z7CF811
10. Any other codes identified by your colleagues in step 1

NOTES: Searches 5 onwards are less specific. If you are from a large practice you may need to apply an age range (eg age over 65 only) to the search to make it manageable for step 4. If you work with care or nursing homes you may wish to also review the notes of these patients, as it is likely that many will have dementia.

** Please be aware that due to different GP computer operating systems you may not be able to find all of the listed read codes above. If you have been unable to find one particular code please just pass on.

Step 4 – Compare search results with QOF dementia register Compare the results of the searches with your practice QOF dementia register. Where discrepancies occur, review the notes to find out whether the patient has a diagnosis of dementia (in which case they can be coded as dementia using the codes in Appendix 1), whether they would benefit from an assessment, or whether they clearly do not have dementia.

Record the results on the form in Appendix 3. NOTE: If you find cases where dementia has been diagnosed but not coded, then it is best to date the diagnosis to the time it was made. This avoids QOF targets inappropriately requesting screening bloods etc.

Step 5 – Discuss patients for further review

At the next practice meeting discuss the list of patients you have identified who might benefit from a memory assessment and consider how best to offer this e.g. visit by usual doctor or letter inviting them to come in for a review.

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Appendix 1 – Read codes

Dementia Read Codes
Dementia in disease EC (Eu02.%)
Senile / presenile organic psych (E00..%)
Vascular dementia (Eu01.%)
Drug-induced dementia (Eu02y1)
Other alcoholic dementia (E012.%)
Dementia in Alzheimer's disease (Eu00.%)
Dementia in conditions EC (E041.)
Delirium superimp dementia (Eu041)
Alzheimer's disease (F110.)
Pick's disease (F111.)
Senile degeneration of brain (F112.)
Lewy body disease (F116.)

Appendix 2 - List of anti-dementia medication

Anti-Dementia drugs
Donepezil (Aricept®, Aricept Evess®)
Galantamine (Reminyl®, Reminyl® XL)
Rivastigmine (Exelon®)
Memantine hydrochloride (Ebixa®)

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Appendix 3 – Results submission form

Please return to …… when completed

Dementia "Coding-clean up" Exercise

Practice Name:

General

Before start of exercise - number on QOF dementia register	
After exercise - number on QOF dementia register	
Number of patients who would benefit from assessment	

Detail

Please note, the numbers in the below table may not add up to totals entered in the table above, as there may be more than one coding issue identified per patient.

		Note – the figures in these three columns should add up to the figure in the total column on the left			
Search	**Total no of patients with this code**	**Number with this code, with confirmed dementia, who were on the QOF dementia register at the start of the exercise**	**Number with this code, with confirmed dementia , who were not on the QOF dementia register at the start of the exercise**	**Number with this code without confirmed dementia**	**Number with this code without confirmed dementia that would benefit from an assessment**
Anti-dementia Drugs					
h/o dementia					
Dementia Monitoring					
Dementia Annual Review					
Cognitive Decline					
Confusion					
Memory loss symptom					
Memory Impairment					
Short term memory problems					
Local codes (please specify) I					
ii					
iii					
iv					

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Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence

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Primary Subject Heading:	General practice / Family practice
Secondary Subject Heading:	Health services research, Epidemiology, Health policy, Mental health, Neurology
Keywords:	Dementia < NEUROLOGY, PRIMARY CARE, PUBLIC HEALTH

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Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence

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ABSTRACT

Objective Improving dementia care is a policy priority nationally and internationally; there is a "diagnosis gap" with less than half of cases of dementia ever diagnosed. In English Health Department's Quality and Outcomes Framework (QOF) encourages primary care recognition and recording of dementia. The codes for dementia are complex with the possibility of under-identification through miscoding. We developed guidance on coding of dementia; we report the impact of applying this to 'clean up' dementia coding and records at a practice level.

Design The guidance had 5 elements: (i) identify Read codes for dementia; (ii) access QOF dementia register; (iii) generate lists of patients who may have dementia; (iv) compare search with QOF data; (v) review cases. In each practice one GP conducted the exercise. The numbers on dementia QOF registers before and after the exercise were recorded with the hours taken to complete the exercise.

Setting London primary care

Participants 23 (85%) of 27 practices participated, covering 79,312 (19,562 over 65s).

Outcomes Numbers on dementia QOF registers; time taken.

Results The numbers on dementia QOF registers increased from 1,007 to 1,139 (χ^2 8.17, p=0.004), raising identification rates by 8.8%. It took 4.7 hours per practice on average.

Conclusions These data demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the dementia identification rate. An improvement of 8.8% between 2011 and 2012 is equivalent to that on the fourth most improved PCT in the UK. In absolute terms, if this effect were mirrored across UK primary care, the number of cases with dementia identified would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46% to 54.8%. Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care.

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ARTICLE SUMMARY

Article focus

- Closing the “diagnosis gap” in dementia is a clinical and policy priority
- The primary care codes used for dementia in the UK are complex with the possibility of under-identification through miscoding.
- We developed guidance on coding of dementia and tested its impact on dementia coding and records at a practice level.

Key messages

- Applying the guidance resulted in a statistically significant increase in the numbers on dementia QOF registers, raising identification rates by 8.8%
- These data demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the dementia identification rate.
- If this effect were mirrored across UK primary care, the number of cases with dementia identified would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46.0% to 54.8%.

Strengths and limitations of this study

- The GPs who took part in this exercise were highly motivated and had been selected to participate in the NHS London dementia fellowship programme
- Generalisability may be limited from these London practices to those in the rest of the UK
- However, the coding systems used and GP information systems vary little so the demonstration that this exercise worked in practices across London may point its being applicable across the UK.
- We achieved a high participation rate and the practices covered a large population (179,312) over a wide and socio-demographically varied set of areas spread across 19 boroughs.
- The protocol generated was simple and required no training

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BACKGROUND

Dementia is one of the most common and serious disorders in later life with a prevalence of 5% and an incidence of 2% per year in the over 65s.[1, 2] In the UK estimates suggest there are 800,000 people with dementia currently.[3] It causes irreversible decline in global intellectual, social and physical functioning. Abnormalities in behaviour, insight and judgement are part of the disorder, as are neuropsychiatric symptoms such as psychosis, anxiety and depression. The economic cost of caring for people with dementia is immense. In the UK the costs of dementia are around £17 billion per year;[3] with some suggesting this is more than stroke, heart disease and cancer.[4] More importantly, the negative impacts of dementia on those with the disorder, in terms of deteriorating function, and on carers[5, 6] are profound. Worldwide there are 35 million people with dementia and this costs $600 billion per year, with these numbers set to double and the costs to at least triple in the next 20 years.[7,8]

The need to improve care for people with dementia is a policy priority nationally and internationally.[9-12] One common finding in analyses of health systems with respect to dementia is that there is a “diagnosis gap” in dementia with less than a half of those with dementia ever attracting a diagnosis of dementia. Also, such diagnosis and contact often occurs late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed. A common element of health strategies to improve the quality of care of people with dementia is the injunction that diagnosis rates should be increased and that diagnosis should be “early” or “timely”.

Part of the Department for Heath for England’s response to this has been to encourage primary care recognition and recording of dementia through its Quality and Outcomes Framework (QOF).[13] This is designed to incentivise, via payment, primary care services to improve the quality of care by standardising improvements in the delivery of primary medical services. The relevant indicators for 2013/2014 include:

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DEM001 The contractor establishes and maintains a register of patients diagnosed with dementia.

The numbers of people with dementia identified on these registers compared with projected numbers from the local age and gender structure has been used as a marker of progress against the goals of the National Dementia Strategy using a commissioned dementia prevalence calculator.[14] Using this methodology, figures from the Alzheimer's Society suggest that diagnosis rates in Britain range from 32% in the East Riding of Yorkshire to 76% in Belfast.[15]

These dementia registers rely on how dementia is coded in primary care record systems. This is generally via Read Codes which are a coded thesaurus of clinical terms that has been used within primary care in the NHS since 1985. The codes available for dementia are complex with the possibility of under-identification through miscoding. NHS London's therefore developed guidance on the coding of dementia (Web Appendix 1). In this paper we report the impact of applying this guidance in a sample of GP practices across London to investigate whether it is possible to raise diagnosis rates through undertaking an exercise to 'clean up' dementia coding and records at a practice level.

METHOD

A coding exercise protocol was developed to enable GPs to conduct a review of practice records and to recode cases where needed. This was developed by PR and SB iteratively with key stakeholders, facilitated by NHS London co-ordinated by JW. The protocol is presented in full in Table 1. This consisted of a simple 5 point process:

Step 1 – Identify commonly used Read codes for dementia/memory concerns

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Step 2 – Obtain practice's QOF dementia register

Step 3 – Run searches to generate lists of patients who may have dementia

Step 4 – Compare search results with QOF dementia register

Step 5 – Discuss patients for further review

Participating practices were drawn from boroughs across London who had a GP on the 2012/13 NHS London GP Dementia Fellowship Programme. The exercise was completed by the GP on the programme in each practice as set out in the Table 1. The numbers identified with dementia on the practice QOF registers before and after the exercise were recorded as were the hours taken to complete the exercise.

RESULTS

Sample

Twenty three (85%) out of the 27 practices available participated. These came from 19 boroughs across London. The participating practices had a practice population of 179,312 with 19,562 (10.9%) over the age of 65. The mean practice size was 8,296 (range 2,543 to 16,700). In terms of representativeness of the sample this proportion over 65 years old was similar to the overall percentage for London (11.2%); the London rate is lower than that for the UK as a whole (16.9%).

Impact of the intervention

The number of people on the practices' dementia QOF registers before the intervention was 1,007; after there were 1,139 cases on the registers (practice population 179,312 with 19,562 aged 65+). This was a statistically significant increase (χ^2 8.17, p=0.004). The mean number of people on the practices' dementia QOF registers before the intervention was 44 (range 0 to 232, standard deviation (sd) 49). After there was an average of 50 cases on the

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registers (range 0 to 248, sd 54); this was a statistically significant difference between those means (t=3.52; p<0.001). Taking the numbers aged 65+ in each practice as the denominator, this represents an identified prevalence of 5.1% before the intervention and 5.8% after. Using the most recent DH estimates,[14] the expected number of people with dementia in London is 69,849 which equates to a prevalence of 8.11% of those aged 65+. We used this to calculate the identification rate before and after the intervention. After the intervention 71.8% of cases of dementia were identified compared with 63.0% before. The effect of the intervention was therefore to increase the rate of identification of dementia in this sample by 8.8%.

Cost of the intervention

The only cost of the intervention was the person time spent on the exercise which took an average of 4.7 hours per practice.

DISCUSSION

The data presented here demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the rate of identification of cases of dementia. In this sample of GP practices in London, an 8.8% improvement was achieved at a cost of an average 4.7 hours of GP time.

Size of effect

We need to consider the meaning of the 8.8% increase observed. In their recent analysis of identification rates from QOF registers across the UK, [15] the Alzheimer's Society calculated for each Primary Care Trust (PCT) area (the forerunners to current Clinical Commissioning Groups (CCGs)) identification rates in the same way that we have here. They did this for 2011 and 2012 and calculated changes in numbers and rank between 2012 and 2011. In rank terms, for a PCT an improvement of 8.8% between 2011 and 2012 would

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have resulted in that PCT being the fourth most improved PCT in the UK (displacing Torbay who achieved an 8.2% improvement). In terms of ranking, an improvement of 8.8% would have moved a PCT up an indicative 68 places (out of 178). In absolute terms, if this were implemented across UK primary care with the same aggregate effect the number of cases with dementia identified on QOF registers would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46.0% to 54.8%.

Reasons for coding error

Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care. Completing the exercise also sheds some light on the reasons for the current coding errors. Part of this may be a wish to avoid labelling patients as having dementia on the QOF register unless there is a high level of certainty as to the diagnosis. This is an understandable and reasonable concern, as there is stigma associated with the diagnosis, and professional attitudes to and confidence in the management of dementia may play a role in perceived under-recognition. However, all the cases re-assigned in this exercise were those with an established dementia. The issues seemed more a function of computer and coding systems. This points to the potential value of exercises such as this. 98% of London practices use EMIS or Vision systems; these require coding by V2-5byte Read codes. In this system there are a large number of potential dementia-related Read codes that might be used and these are not presented in a way that is user friendly (Web Appendix 1). In this exercise we sought to address this by operationalising how these codes should be used. Equally the letters received by GPs from secondary care services where diagnoses may have been made were often not clear in terms of diagnosis and diagnostic category. Letters from psychiatric services were often long with the diagnosis often hidden in the text. We also found cases where the first assessment letter referred to “probable dementia” but where the definitive diagnosis in a letter 3-6 months later had not led to the coding being brought up to date. The use of multiple systems and unfamiliar terminologies by secondary care leads to confusion and lack of clarity in coding within primary care. The

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simple expedient of all secondary care clearly stating the ICD 10 codes or the most appropriate Read code to use would address this coding problem.

Limitations

This is a simple pragmatic study and the limitations of this exercise and the data presented here need to be considered. This was not a random sample of practices or of GPs. The GPs who took part in this exercise were highly motivated and had been selected to participate in the NHS London dementia fellowship programme. They were therefore interested in dementia and also built skills during the programme within which the exercise was completed. The main likely impact of this may have been to enable them to complete the exercise more quickly than the average GP. However, even if the exercise took twice the time, this would mean that it could be achieved in a single day. The generalisability of the practices within which the exercise was completed also needs to be considered. All were group practices and they were similar to the rest of London in terms of age structure, however the practices studied had a higher than average recognition rate before the exercise (63.0%) compared with the UK as a whole (46.0%). This may reflect the interests of the participating GPs and their effect on coding in those practices. This is of interest because this suggests that we were intervening in practice systems that may have been more optimised than others might be. It is quite possible that in less optimised systems there might be greater levels of coding error and so an even greater effect might be achieved. As an estimate of effect our results might therefore be considered conservative. There will be differences between London practices and those in the rest of the UK as evidenced by the difference in age structure in London compared with the UK as a whole. However, the coding systems used and GP information systems vary less, and so the demonstration that this exercise worked in practices across London may point its being applicable across the UK. Different countries have different systems and it is likely that the detail of the approach here will only apply to the UK, however the general issue of clarity in coding is likely to be of importance internationally. There are strengths in the approach

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used. We achieved a high participation rate and the practices covered a large population (179,312) over a wide and socio-demographically varied set of areas spread across 19 boroughs. Also, the protocol generated was simple and required no training. The data here represent a test of the feasibility of conducting the exercise and of the content of the protocol.

Conclusions

It is important to be clear that this coding exercise would form only a part of comprehensive whole system effort to improve dementia care and to lift diagnosis rates through initiatives such as: education and training, memory service commissioning, and service improvement. But, the results presented here suggest that completing this exercise could provide a simple, cheap and useful first step to improve accuracy of records. More accurate information can help improve the management of patients and also help to close the diagnosis gap.[11, 16] In terms of next steps, evaluations of its effect in a more representative sample of practices nationwide would be of use. But equally, given its simplicity and low cost, it may be that practices and CCGs would wish to implement this without needing further evaluation other than auditing local effects. In this paper we provide all the materials needed to carry out the exercise.

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Competing interests statement: Sube Banerjee: has received consultancy fees, speakers' fees, research funding or educational support to attend conferences from pharmaceutical companies involved in the manufacture of antidepressants and antidementia drugs, and has been employed by the Department of Health for England. Jen Watt: has been employed by NHS London. None other.

Data sharing

No additional data available.

Contributorship

All authors were involved in the design and conduct of the project; all but JW and SB carried out the exercise and collected the data. All participated in the editing the paper and all agreed the final content. PR and SB generated the coding protocol. Analyses were carried out by SB who also wrote the first draft of this paper. SB is the guarantor of this research.

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WEB APPENDIX 1 – LONDON DEMENTIA CODING GUIDANCE

Guidance on Dementia Coding

NHS London

What is the big issue for London GPs in coding dementia?

There is a dementia diagnosis gap of 52% in London, which means that only 48% of those who we would expect to have dementia, based on population prevalence rates, are recorded on GP practice dementia registers[1]. We believe one of the reasons behind this apparently low diagnosis rate is a lack of accurate coding due to there being confusion with the available codes. This note for GPs contains guidance to help with this.

Why is it so important diagnose and accurately code dementia?

1. It means the patient's care can be planned, managed and monitored, so that they can be signposted to supportive services and prescribed appropriate medication.
2. Diagnosis gives power to the patient and their families, as it brings clarity in terms of what is happening to them, and provides them with the ability to make choices themselves (National Dementia Strategy, 2009).
3. The coding of dementia and putting the patient on the dementia register means we can develop an accurate picture of London dementia rates to inform commissioning of high quality, cost effective services in response.
4. It means that GPs can see their own practice performance rise, and give patients confidence as they can see the identification rates on www.myhealthlondon.nhs.uk

Making dementia coding simple

The coding of dementia can be less than straightforward, so a team of GPs working to improve dementia care in London, with support from specialist experts, has put together this GP dementia coding guideline.

Guideline

1. We propose the use of four codes in primary care, which are listed below.
2. If the specific type of dementia is unknown, for whatever reason, please use the code Eu02z **"Unspecified dementia"**. This can always be changed later when more information is available. Please do not use 1461.00 "h/o dementia", 28E..00 "cognitive decline" or similar codes for this purpose – these do not allow aggregation.
3. Where some diagnostic data are available the codes Eu00. can be used for Alzheimer's disease, Eu002 for mixed dementia, and Eu01. for vascular dementia. All others can be given Eu02z.
4. A full list dementia codes can be found below. This matches ICD10 codes to recognised general practice dementia READ codes. Where detailed information on subtype of dementia is available, then these can be used.

The main codes which General Practitioners should use to code for dementia in primary care are:

ICD		Read
F00	Dementia in Alzheimer's disease	Eu00.
F00.2	Dementia in Alzheimer's disease, atypical or mixed type ("Mixed Dementia")	Eu002
F01	Vascular dementia	Eu01.
F03	Unspecified dementia	Eu02z

[1] QOF data, 2010/11

Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia Feb, 2012

APPENDIX

ICD10		READ
F00	Dementia in Alzheimer's disease	Eu00.
F00.0	Dementia in Alzheimer's disease with early onset	Eu000
F00.1	Dementia in Alzheimer's disease with late onset	Eu001
F00.2	Dementia in Alzheimer's disease, atypical or mixed type	Eu002
F00.9	Dementia in Alzheimer's disease, unspecified	Eu00z
F01	Vascular dementia Arteriosceloritic dementia	Eu01. E004
F01.1	Multi-infarct dementia	Eu011
F01.2	Subcortical vascular dementia	Eu012
F01.3	Mixed cortical and subcortical vascular dementia	Eu013
F01.8	Other vascular dementia	Eu01y
F01.9	Vascular dementia, unspecified Uncomplicated arteriosclerotic dementia Arteriosclerotic dementia with delirium Arteriosclerotic dementia with paranoia Arteriosclerotic dementia with depression Arteriosclerotic dementia NOS	Eu01z E0040 E0041 E0042 E0043 E004z
F02	Dementia in other diseases classified elsewhere	Eu02.
F02.0	Dementia in Pick's disease	Eu020
F02.1	Dementia in Creutzfeldt-Jakob disease	Eu021
F02.2	Dementia in Huntingdon's disease	Eu022
F02.3	Dementia in Parkinson's disease	Eu023
F02.4	Dementia in HIV disease	Eu024
F02.8	Dementia in other disease classified elsewhere Dementia in conditions	Eu02y E041
F03	Unspecified dementia Presenile dementia Uncomplicated presenile dementia Presenile dementia with delirium Presenile dementia with paranoia Presenile dementia with depression Presenile dementia NOS Uncomplicated senile dementia Senile dementia with depressive or paranoid features Senile dementia with paranoia Senile dementia with depression Senile dementia with depressive or paranoid features NOS	Eu02z E001. E0010 E0011 E0012 E0013 E001z E000 E002 E0020 E0021 E002z

ICD10		READ
F05.1	Delirium superimposed on dementia Senile dementia with delirium	Eu041 E003
F05.9	Delirium, unspecified	Eu04z
F06.0	Organic hallucinosis Other senile and presenile organic psychoses Senile or presenile psychoses	Eu060 E00y E00z
F06.7	Mild cognitive disorder	Eu067
F10.7	Residual and late onset psychotic disorder due to alcohol. Including; - Alcoholic dementia - Other alcoholic dementia - Chronic alcoholic brain syndrome	Eu107 Eu10711 E012 E0120
G30 G30.8 G30.9	Alzheimer's disease Other Alzheimer's disease Alzheimer's disease, unspecified	F110.
G30.0	Alzheimer's disease with early onset	F1100
G30.1	Alzheimer's disease with late onset	F1101
G31.0	Circumscribed brain atrophy Including; - Fronto-temporal dementia - Pick's disease - Progressive isolated aphasia	 No Code F111.
G31.1	Senile degeneration of the brain, not elsewhere classified	F112.
G31.8	Other specified degenerative disease of the nervous system Including - Grey matter degeneration - Lewy body disease - Lewy body dementia - Subacute necrotizing encephalopathy	 F116 Eu025

"Knowledge is power with respect to diagnosis, giving those affected and their families an understanding of what is happening and the ability to make choices themselves"

National Dementia Strategy, 2009

For a copy of the London Dementia Needs Assessment or any queries about dementia diagnosis and care, please get in touch with Jen.Watt@london.nhs.uk ; 020 7932 2646

Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia Feb, 2012

Table 1: Dementia coding exercise protocol

Dementia "Coding Clean-up" Exercise:
Improving records of dementia diagnosis in your practice by more accurate coding

Introduction - why is this important? Achieving early diagnosis of dementia is a major national priority, identified in the National Dementia Strategy and championed by the Government. Only 46% of those who we would expect to have dementia in London, based on population prevalence rates, are recorded on GP practice dementia registers[1]. We believe one of the reasons behind this low diagnosis rate is problems in coding. We have previously developed guidance for GPs to support them to code dementia diagnoses accurately (see Appendix 4).

Aims The following exercise has been primarily designed to support GPs to identify problems in coding, which are contributing to low rates of dementia diagnosis on practice registers. It also provides a framework for GPs, to consider other patients who may have dementia, but are not yet diagnosed. It may also identify patients who have been lost to follow-up, which GPs can then address following local pathways.

Method

Step 1 – Identify commonly used Read codes for dementia/memory concerns At a practice meeting, discuss what codes GPs in your practice use when adding dementia or worries about memory to a patient's problem list. Make a note of codes commonly used by your colleagues. Add any codes commonly used that are not already included on the list[2] in step 3 below.

Step 2 – Obtain Practice's QOF dementia register Find the QOF dementia register for your practice[3]. Write the number of patients currently on the register, on the form in Appendix 3.

Step 3 – Run searches to generate lists of patients who may have dementia[4] Run the following searches:

1. All those prescribed anti-dementia medication (See Appendix 2)
2. "h/o dementia" Read code 1461.00
3. "Dementia monitoring" Read code 66h..00
4. "Dementia annual review" Read code 6AB..00
5. "Cognitive decline" Read code 28E..00

[1] Dementia Prevalence Calculator, 2013
[2] These are the Read codes that were identified by the London pilot as being most commonly used. There is, however, variation from practice to practice, so it is important to have the discussion with colleagues, to identify codes your practice commonly uses. For example, other codes used in some practices in the pilot were: "Forgetful", "Organic memory impairment", "Short Term Memory Loss"
[3] For EMIS and Vision, the codes that place patients on the QOF dementia register can be found in Appendix 1

[4] It is possible that this part of the exercise can be done by your practice manager/ administrator

6. "Confusion" Read code R009.00
7. "Memory loss Symptom" Read code 1B1A.
8. "Memory Impairment" Read code Z7CEH
9. "Short Term Memory Problems" Read code Z7CF811
10. Any other codes identified by your colleagues in step 1

NOTES: Searches 5 onwards are less specific. If you are from a large practice you may need to apply an age range (eg age over 65 only) to the search to make it manageable for step 4. If you work with care or nursing homes you may wish to also review the notes of these patients, as it is likely that many will have dementia.

** Please be aware that due to different GP computer operating systems you may not be able to find all of the listed read codes above. If you have been unable to find one particular code please just pass on.

Step 4 – Compare search results with QOF dementia register Compare the results of the searches with your practice QOF dementia register. Where discrepancies occur, review the notes to find out whether the patient has a diagnosis of dementia (in which case they can be coded as dementia using the codes in Appendix 1), whether they would benefit from an assessment, or whether they clearly do not have dementia.

Record the results on the form in Appendix 3. NOTE: If you find cases where dementia has been diagnosed but not coded, then it is best to date the diagnosis to the time it was made. This avoids QOF targets inappropriately requesting screening bloods etc.

Step 5 – Discuss patients for further review

At the next practice meeting discuss the list of patients you have identified who might benefit from a memory assessment and consider how best to offer this e.g. visit by usual doctor or letter inviting them to come in for a review.

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Appendix 1 – Read codes

Dementia Read Codes
Dementia in disease EC (Eu02.%)
Senile / presenile organic psych (E00..%)
Vascular dementia (Eu01.%)
Drug-induced dementia (Eu02y1)
Other alcoholic dementia (E012.%)
Dementia in Alzheimer's disease (Eu00.%)
Dementia in conditions EC (E041.)
Delirium superimp dementia (Eu041)
Alzheimer's disease (F110.)
Pick's disease (F111.)
Senile degeneration of brain (F112.)
Lewy body disease (F116.)

Appendix 2 - List of anti-dementia medication

Anti-Dementia drugs
Donepezil (Aricept®, Aricept Evess®)
Galantamine (Reminyl®, Reminyl® XL)
Rivastigmine (Exelon®)
Memantine hydrochloride (Ebixa®)

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Appendix 3 – Results submission form

Please return to …… when completed

Dementia "Coding-clean up" Exercise

Practice Name:

General

Before start of exercise - number on QOF dementia register	
After exercise - number on QOF dementia register	
Number of patients who would benefit from assessment	

Detail

Please note, the numbers in the below table may not add up to totals entered in the table above, as there may be more than one coding issue identified per patient.

		Note – the figures in these three columns should add up to the figure in the total column on the left			
Search	**Total no of patients with this code**	**Number with this code, with confirmed dementia, who were on the QOF dementia register at the start of the exercise**	**Number with this code, with confirmed dementia , who were not on the QOF dementia register at the start of the exercise**	**Number with this code without confirmed dementia**	**Number with this code without confirmed dementia that would benefit from an assessment**
Anti-dementia Drugs					
h/o dementia					
Dementia Monitoring					
Dementia Annual Review					
Cognitive Decline					
Confusion					
Memory loss symptom					
Memory Impairment					
Short term memory problems					
Local codes (please specify) I					
ii					
iii					
iv					

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Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence

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Dr David Davies, GP Islington CCG, London UK
Dr Sid Deshmukh, GP Bexley CCG, London UK
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Dr Dominic Naidoo, GP Kingston CCG, London UK
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Key words: primary care, dementia, coding, case registers, QOF, diagnosis rates

Word count: 2,1313~~13~~

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ABSTRACT

Objective Improving dementia care is a policy priority nationally and internationally; there is a "diagnosis gap" with less than half of cases of dementia ever diagnosed. In English Health Department's Quality and Outcomes Framework (QOF) encourages primary care recognition and recording of dementia. The codes for dementia are complex with the possibility of under-identification through miscoding. We developed guidance on coding of dementia; we report the impact of applying this to 'clean up' dementia coding and records at a practice level.

Design The guidance had 5 elements: (i) identify Read codes for dementia; (ii) access QOF dementia register; (iii) generate lists of patients who may have dementia; (iv) compare search with QOF data; (v) review cases. In each practice one GP conducted the exercise. The numbers on dementia QOF registers before and after the exercise were recorded with the hours taken to complete the exercise.

Setting London primary care

Participants 23 (85%) of 27 practices participated, covering 79,312 (19,562 over 65s).

Outcomes Numbers on dementia QOF registers; time taken.

Results The numbers on dementia QOF registers increased from 1,007 to 1,139 (χ^2 8.17, p=0.004), raising identification rates by 8.8%. It took 4.7 hours per practice on average.

Conclusions These data demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the dementia identification rate. An improvement of 8.8% between 2011 and 2012 is equivalent to that on the fourth most improved PCT in the UK. In absolute terms, if this effect were mirrored across UK primary care, the number of cases with dementia identified would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46% to 54.8%. Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care.

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ARTICLE SUMMARY

Article focus

- Closing the “diagnosis gap” in dementia is a clinical and policy priority
- The primary care codes used for dementia in the UK are complex with the possibility of under-identification through miscoding.
- We developed guidance on coding of dementia and tested its impact on dementia coding and records at a practice level.

Key messages

- Applying the guidance resulted in a statistically significant increase in the numbers on dementia QOF registers, raising identification rates by 8.8%
- These data demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the dementia identification rate.
- If this effect were mirrored across UK primary care, the number of cases with dementia identified would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46.0% to 54.8%.

Strengths and limitations of this study

- The GPs who took part in this exercise were highly motivated and had been selected to participate in the NHS London dementia fellowship programme
- Generalisability may be limited from these London practices to those in the rest of the UK
- However, the coding systems used and GP information systems vary little so the demonstration that this exercise worked in practices across London may point its being applicable across the UK.
- We achieved a high participation rate and the practices covered a large population (179,312) over a wide and socio-demographically varied set of areas spread across 19 boroughs.
- The protocol generated was simple and required no training

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BACKGROUND

Dementia is one of the most common and serious disorders in later life with a prevalence of 5% and an incidence of 2% per year in the over 65s.[1, 2] In the UK estimates suggest there are 800,000 people with dementia currently.[3] It causes irreversible decline in global intellectual, social and physical functioning. Abnormalities in behaviour, insight and judgement are part of the disorder, as are neuropsychiatric symptoms such as psychosis, anxiety and depression. The economic cost of caring for people with dementia is immense. In the UK the costs of dementia are around £17 billion per year;[3] with some suggesting this is more than stroke, heart disease and cancer.[4] More importantly, the negative impacts of dementia on those with the disorder, in terms of deteriorating function, and on carers[5, 6] are profound. Worldwide there are 35 million people with dementia and this costs $600 billion per year, with these numbers set to double and the costs to at least triple in the next 20 years.[7,8]

The need to improve care for people with dementia is a policy priority nationally and internationally.[9-12] One common finding in analyses of health systems with respect to dementia is that there is a “diagnosis gap” in dementia with less than a half of those with dementia ever attracting a diagnosis of dementia. Also, such diagnosis and contact often occurs late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed. A common element of health strategies to improve the quality of care of people with dementia is the injunction that diagnosis rates should be increased and that diagnosis should be “early” or “timely”.

Part of the Department for Heath for England’s response to this has been to encourage primary care recognition and recording of dementia through its Quality and Outcomes Framework (QOF).[13] This is designed to incentivise, via payment, primary care services to improve the quality of care by standardising improvements in the delivery of primary medical services. The relevant indicators for 2013/2014 include:

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DEM001 The contractor establishes and maintains a register of patients diagnosed with dementia.

The numbers of people with dementia identified on these registers compared with projected numbers from the local age and gender structure has been used as a marker of progress against the goals of the National Dementia Strategy using a commissioned dementia prevalence calculator.[14] Using this methodology, figures from the Alzheimer's Society suggest that diagnosis rates in Britain range from 32% in the East Riding of Yorkshire to 76% in Belfast.[15]

These dementia registers rely on how dementia is coded in primary care record systems. This is generally via Read Codes which are a coded thesaurus of clinical terms that has been used within primary care in the NHS since 1985. The codes available for dementia are complex with the possibility of under-identification through miscoding. NHS London's therefore developed guidance on the coding of dementia (Web Appendix 1). In this paper we report the impact of applying this guidance in a sample of GP practices across London to investigate whether it is possible to raise diagnosis rates through undertaking an exercise to 'clean up' dementia coding and records at a practice level.

METHOD

A coding exercise protocol was developed to enable GPs to conduct a review of practice records and to recode cases where needed. This was developed by PR and SB iteratively with key stakeholders, facilitated by NHS London co-ordinated by JW. The protocol is presented in full in Table 1. This consisted of a simple 5 point process:

Step 1 – Identify commonly used Read codes for dementia/memory concerns

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Step 2 – Obtain practice's QOF dementia register

Step 3 – Run searches to generate lists of patients who may have dementia

Step 4 – Compare search results with QOF dementia register

Step 5 – Discuss patients for further review

Participating practices were drawn from boroughs across London who had a GP on the 2012/13 NHS London GP Dementia Fellowship Programme. The exercise was completed by the GP on the programme in each practice as set out in the Table 1. The numbers identified with dementia on the practice QOF registers before and after the exercise were recorded as were the hours taken to complete the exercise.

RESULTS

Sample

Twenty three (85%) out of the 27 practices available participated. These came from 19 boroughs across London. The participating practices had a practice population of 179,312 with 19,562 (10.9%) over the age of 65. The mean practice size was 8,296 (range 2,543 to 16,700). In terms of representativeness of the sample this proportion over 65 years old was similar to the overall percentage for London (11.2%); the London rate is lower than that for the UK as a whole (16.9%).

Impact of the intervention

The number of people on the practices' dementia QOF registers before the intervention was 1,007; after there were 1,139 cases on the registers (practice population 179,312 with 19,562 aged 65+). This was a statistically significant increase (χ^2 8.17, p=0.004). The mean number of people on the practices' dementia QOF registers before the intervention was 44 (range 0 to 232, standard deviation (sd) 49). After there was an average of 50 cases on the

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registers (range 0 to 248, sd 54); this was a statistically significant difference between those means (t=3.52; p<0.001). Taking the numbers aged 65+ in each practice as the denominator, this represents an identified prevalence of 5.1% before the intervention and 5.8% after. Using the most recent DH estimates,[14] the expected number of people with dementia in London is 69,849 which equates to a prevalence of 8.11% of those aged 65+. We used this to calculate the identification rate before and after the intervention. After the intervention 71.8% of cases of dementia were identified compared with 63.0% before. The effect of the intervention was therefore to increase the rate of identification of dementia in this sample by 8.8%.

Cost of the intervention

The only cost of the intervention was the person time spent on the exercise which took an average of 4.7 hours per practice.

DISCUSSION

The data presented here demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the rate of identification of cases of dementia. In this sample of GP practices in London, an 8.8% improvement was achieved at a cost of an average 4.7 hours of GP time.

Size of effect

We need to consider the meaning of the 8.8% increase observed. In their recent analysis of identification rates from QOF registers across the UK, [15] the Alzheimer's Society calculated for each Primary Care Trust (PCT) area (the forerunners to current Clinical Commissioning Groups (CCGs)) identification rates in the same way that we have here. They did this for 2011 and 2012 and calculated changes in numbers and rank between 2012 and 2011. In rank terms, for a PCT an improvement of 8.8% between 2011 and 2012 would

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have resulted in that PCT being the fourth most improved PCT in the UK (displacing Torbay who achieved an 8.2% improvement). In terms of ranking, an improvement of 8.8% would have moved a PCT up an indicative 68 places (out of 178). In absolute terms, if this were implemented across UK primary care with the same aggregate effect the number of cases with dementia identified on QOF registers would rise by over 70,000 from 364,329 to 434,488 raising the recognition rate from 46.0% to 54.8%.

Reasons for coding error

Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care. Completing the exercise also sheds some light on the reasons for the current coding errors. Part of this may be a wish to avoid labelling patients as having dementia on the QOF register unless there is a high level of certainty as to the diagnosis. This is an understandable and reasonable concern, as there is stigma associated with the diagnosis, and professional attitudes to and confidence in the management of dementia may play a role in perceived under-recognition. However, all the cases re-assigned in this exercise were those with an established dementia. The issues seemed more a function of computer and coding systems. This points to the potential value of exercises such as this. 98% of London practices use EMIS or Vision systems; these require coding by V2-5byte Read codes. In this system there are a large number of potential dementia-related Read codes that might be used and these are not presented in a way that is user friendly (Web Appendix 1). In this exercise we sought to address this by operationalising how these codes should be used. Equally the letters received by GPs from secondary care services where diagnoses may have been made were often not clear in terms of diagnosis and diagnostic category. Letters from psychiatric services were often long with the diagnosis often hidden in the text. We also found cases where the first assessment letter referred to “probable dementia” but where the definitive diagnosis in a letter 3-6 months later had not led to the coding being brought up to date. The use of multiple systems and unfamiliar terminologies by secondary care leads to confusion and lack of clarity in coding within primary care. The

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simple expedient of all secondary care clearly stating the ICD 10 codes or the most appropriate Read code to use would address this coding problem.

Limitations

This is a simple pragmatic study and the limitations of this exercise and the data presented here need to be considered. This was not a random sample of practices or of GPs. The GPs who took part in this exercise were highly motivated and had been selected to participate in the NHS London dementia fellowship programme. They were therefore interested in dementia and also built skills during the programme within which the exercise was completed. The main likely impact of this may have been to enable them to complete the exercise more quickly than the average GP. However, even if the exercise took twice the time, this would mean that it could be achieved in a single day. The generalisability of the practices within which the exercise was completed also needs to be considered. All were group practices and they were similar to the rest of London in terms of age structure, however the practices studied had a higher than average recognition rate before the exercise (63.0%) compared with the UK as a whole (46.0%). This may reflect the interests of the participating GPs and their effect on coding in those practices. This is of interest because this suggests that we were intervening in practice systems that may have been more optimised than others might be. It is quite possible that in less optimised systems there might be greater levels of coding error and so an even greater effect might be achieved. As an estimate of effect our results might therefore be considered conservative. There will be differences between London practices and those in the rest of the UK as evidenced by the difference in age structure in London compared with the UK as a whole. However, the coding systems used and GP information systems vary less, and so the demonstration that this exercise worked in practices across London may point its being applicable across the UK. Different countries have different systems and it is likely that the detail of the approach here will only apply to the UK, however the general issue of clarity in coding is likely to be of importance internationally. There are strengths in the approach

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used. We achieved a high participation rate and the practices covered a large population (179,312) over a wide and socio-demographically varied set of areas spread across 19 boroughs. Also, the protocol generated was simple and required no training. The data here represent a test of the feasibility of conducting the exercise and of the content of the protocol.

Conclusions

It is important to be clear that this coding exercise would form only a part of comprehensive whole system effort to improve dementia care and to lift diagnosis rates through initiatives such as: education and training, memory service commissioning, and service improvement. But, the results presented here suggest that completing this exercise could provide a simple, cheap and useful first step to improve accuracy of records. More accurate information can help improve the management of patients and also help to close the diagnosis gap.[11, 16] In terms of next steps, evaluations of its effect in a more representative sample of practices nationwide would be of use. But equally, given its simplicity and low cost, it may be that practices and CCGs would wish to implement this without needing further evaluation other than auditing local effects. In this paper we provide all the materials needed to carry out the exercise.

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Competing interests statement: Sube Banerjee: has received consultancy fees, speakers' fees, research funding or educational support to attend conferences from pharmaceutical companies involved in the manufacture of antidepressants and antidementia drugs, and has been employed by the Department of Health for England. Jen Watt: has been employed by NHS London. None other.

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